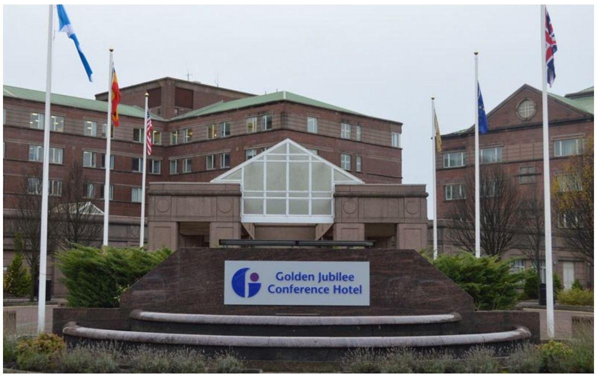
Health Literacy at the Deep End: Addressing Health Inequalities

18 March 2016

Golden Jubilee Conference Hotel

Conference Proceedings



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Welcome Note: Dr Jo Protheroe and Dr Graham Kramer

Conference Co-Chairs

Dear all…………

I am delighted to welcome you to the fourth one-day conference of the **Health Literacy Group UK** which this year is made even more exciting by joining with Graham Kramer and his colleagues within Scottish Government's Person Centred Team along with members of the Scottish Health Literacy Action Plan implementation Group (SHLAPIG). The Health Literacy UK Group, initially funded by the English Department of Health, and supported by the Society of Academic Primary Care, was set up in 2007. Our aims were to build a 'critical mass' of stakeholders interested in health literacy research and practice in England; sharing skills, experience and ideas; and supporting members to develop the evidence on the impact that health literacy has on people and communities in the UK.

The last nine years have seen exciting growth. We now have over 700 active members, and a diverse and exciting regular seminar programme, where different health literacy topics can be explored in depth at various locations around the UK. Health Literacy as an important Public Health concern has gained momentum in England, Scotland, Wales and Ireland – we are reaching a 'tipping point' where hopefully policy makers will sit up and take notice! So this is an exciting and propitious time for our conference, where the health literacy community across the UK will have the chance to present, listen to and learn from each other about current projects and emerging findings.

We have been delighted by both the quality and quantity of the abstracts submitted for presentation. Health literacy is emerging as important in the UK on so many levels – for people striving to become and stay healthy, for the health service and educational community as we support people to develop new skills.

I would like to give mention and special thanks to several people who have been instrumental in the success of the Health Literacy Group UK. Firstly, I'll like to thank the steering group who have all made a major contribution to our success and to organising this conference. We simply wouldn't have achieved what we have without their tireless efforts: Gill Rowlands, Cath Jackson, Bernadette Bartlem, Emma Brooks, Janet Solla, Emee Estacio, Mike Oliver and especially Sue Weir have each played a key role, and we are very grateful.

As this is a Four Nation Event (no rugby involved!) we have a very broad Conference Organising Committee who have helped to pull together what we hope is an inspiring and stimulating conference. My thanks go to my Co-Chair Graham Kramer, Blythe Robertson, Evelyn McElhinney, Christine Hoy, Kate Burton, Lindsey Murphy, Claire Steven, Lesley Munroe, Anne Wales, Phyllis Easton, Jo Develin and Anne McCusker for their time and input into the planning of this event.

On behalf of the Conference Committee I would also like to thank our Speakers, Maureen Watt MSP, Dr Catherine Calderwood, Prof Graham Watt, Dr Bernadette Cullen, Prof Adrian Edwards and all our workshop, oral and poster presenters for taking the time to join us and share their expertise.

Finally – we do hope everyone attending has a really good time. Have a great conference, and we hope to continue working with you in the future.

Best wishes

Jo Protheroe, Chair of Health Literacy group UK and Conference Co-Chair

On behalf of Scottish Government's Person Centred Team and Scotland's Health Literacy Action Plan Implementation Group I too am delighted to welcome you all to Glasgow. 18 months ago after the 3rd UK Health Literacy Group Conference in Keele, Jo and Gill Rowlands mooted the idea of holding the next conference in Scotland. I am delighted the idea has grown into reality.
It's been a real privilege to work collaboratively with fellow pioneers of health literacy from across the UK, focussing on the troubling issue of health inequalities. All of us here today are part of a small but growing movement that is responding to the, often challenging, health literacy needs of individuals and communities. I hope this day will be a stimulating and motivating opportunity to share and network.

Graham Kramer
Conference co-chair

Best wishes

Graham Kramer
National Clinical Lead for Self-Management and Health Literacy, Scotland

Members of the Conference Organising Committee

Jo Protheroe (Co-Chair)

Jo joined Keele University as a Senior Lecturer in General Practice in 2011 and continues to practice as a GP in Manchester. Her research, influenced by her clinical practice as a GP in inner-city Manchester, is focused on two NHS priorities - the needs of socio-economically disadvantaged patients and the need for interventions to improve patient self-management in long-term conditions. Research has shown that patients with low health literacy have difficulty in participating in their health care, resulting in poorer health. She is Chair of the Health Literacy UK (www.healthliteracy.org.uk) group.

Graham Kramer (Co-Chair)

Dr Graham Kramer has been a GP at Annat Bank Practice, in Montrose, Tayside for the last 20 years. He has had a strong interest in the primary care management of people living with long term conditions and the challenge of delivering person-centred care and supporting self-management. In 2004 he had a sabbatical in New Zealand studying a postgraduate diploma in General Practice.

Since 2011 he has been working part-time with Scottish Government, within the Person Centred Health and Care Team as National Clinical Lead for Self-management and Health Literacy. His work has been looking at ways healthcare and polices can support and enable people with long term conditions to have more confidence, understanding, knowledge and skills to be in the driving seat of their health and care.

Conference Organising Committee
Bernadette Bartlam
Emma Brooks
Kate Burton
Bernadette Cullen
Jo Develin
Phyllis Easton
Emee Estacio
Christine Hoy
Cath Jackson
Anne McCusker
Evelyn McElhinney
Lesley Munroe
Lindsey Murphy
Blythe Robertson
Gill Rowlands
Janet Solla
Claire Steven
Anne Wales
Sue Weir

Health Literacy Group UK
Bernadette Bartlam
Emma Brooks
Emee Estacio
Cath Jackson
Mike Oliver
Gill Rowlands
Janet Solla

Conference Programme

9.30-10.00	**Coffee and registration**				
10.00-10.15	**Welcome** – *Dr Jo Protheroe, Chair of Health Literacy Group UK* **Opening Speaker** - *Maureen Watt MSP, Minister for Public Health, Scotland*				
10.15-11.30	**Presentations by an Expert Panel** Session Chair - *Maureen Watt MSP, Minister for Public Health, Scotland* Scotland – *Professor Graham Watt, University of Glasgow* England – *Dr Jo Protheroe, Health Literacy Group UK* Northern Ireland – *Dr Bernadette Cullen, Belfast Healthy Cities* Wales – *Professor Adrian Edwards, Cardiff University*				
11.30-11.55	**Coffee, posters and networking**				
11.55-13.00	**Parallel Presentations**				
	Critical and Communicative Health Literacy *Chair: Christine Hoy* *Health and Social Care Alliance Scotland*	Health Literacy and the Healthcare Workforce *Chair: Kate Burton* *NHS Lothian*	Health Literacy, Mental and Physical Health *Chair: Cath Jackson* *University of York*	Co-creating Health and Health Literacy *Chair: Gill Rowlands* *University of Newcastle and Aarhus University*	Health Literacy and Intellectual Disabilities *Chair: Bernadette Bartlam* *Keele University*
11.55-12.10	Understanding Health Research *Amy Nimegeer* *University of Glasgow*	Building workforce capability for health literacy *Lindsey Murphy* *NHS Education for Scotland*	Older People, Mental Health and Wellbeing: A Mixed Methods Study *Sara Rodgers* *University of York*	Developing a film about cervical screening for Black and Minority Ethnic (BME) women with low health literacy *Jonathan Berry* *NHS England*	What makes information accessible within healthcare settings: insights from a learning disability context *Dominic Jarrett* *NHS Ayrshire and Arran*

12.10-12.25	Critical health literacy as a capability: developing critical health literacy among migrant and ethnic minority groups *Christalla Pithara* *Keele University*	Healthcare providers' views about how to develop health literacy in an older adult population *Charlotte Brooks* *University of Southampton*	Health Literacy in a young offender prison population *Anita Mehay* *University of London*	HEY! (Healthy Eating for Young Children) *Janet Solla* *Community Health and Learning Foundation*	Developing an action plan which improves access to health information and addresses health literacy *Clare Black* *NHS Ayrshire and Arran*
12.25-12.40	Communication and community health literacy in Dien Bien Province, Vietnam: a qualitative study *Shannon McKinn* *The University of Sydney*	Improving numeracy among NHS support workers and attitudes to learning across Trusts *Hannah Cowan* *London School of Hygiene and Tropical Medicine*	Investigating the impact of health literacy in individuals with chronic pain *Laura Mackey* *University College Dublin*	What patient and public involvement is there in research on health literacy: A descriptive critical review *Stephanie Howard Wilsher* *University of East Anglia*	The Easy Read Project. Comprehension of 'easy read' health-related text by people with intellectual disabilities *Susan Buell* *University of East Anglia*
12.40-12.55	Health literacy practices in a 3D social virtual world: A social model of health literacy *Evelyn McElhinney* *Glasgow Caledonian University*	Nurses' perceptions of health literacy in adolescent patients: A qualitative descriptive study *Leslie Malloy-Weir* *University of Saskatchewan*	Health Literacy and Diabetes Management among South Asians in the UK: A Photovoice Study *Bushra Bibi* *Keele University*	Supporting the public's health literacy by developing services through community pharmacies - A Pilot project *Tania Cork* *Stoke Local Pharmaceutical Committee*	
13.00-14.00	**Lunch, posters and networking**				
14.00-14.50	**Keynote Speaker** – *Dr Catherine Calderwood, Chief Medical Officer, Scotland* **Session Chair** - *Dr Graham Kramer, National Clinical Lead for Self-Management and Health Literacy, Scotland*				
14.50-15.15	**Coffee, posters and networking**				
15.15-16.30	**Workshops**				
	Health literacy in Scotland – sharing our learning and ideas	Health Literacy within current practice: applying essential criteria	Ophelia	Learner-centred Health Literacy	Towards Sexual Health Literacy
16.30-16.45	**Poster Prize and Closing Remarks** *Dr Graham Kramer, National Clinical Lead for Self-Management and Health Literacy, Scotland* *Dr Jo Protheroe, Chair of Health Literacy Group UK*				

Keynote Speakers

Maureen Watt (MSP), Minister for Public Health, Scotland

Maureen Watt entered the Scottish Parliament in April 2006 and became the first MSP to take the oath in Doric as well as English. Coming from a farming family and having worked in education, finance and the oil sector, she is a passionate advocate for the North-East, in history and culture. She was appointed Minister of Public Health in November 2014.

Dr Bernadette Cullen, Belfast Healthy Cities

Dr Cullen graduated in Medicine from Queens University Belfast, and worked in hospital medicine for a few years before deciding to specialise in Public Health. Following completion of her specialist training, which included a Masters at Edinburgh University and professional exams, Dr Cullen obtained a Consultant in Public Health post. She worked in the Eastern Health and Social Services Board for nineteen years and, following health service restructuring in 2009, in the regional Public Health Agency based in Belfast. Her main areas of interest and responsibility included population Screening Programmes and Health Improvement, she was regional lead for Sexual Health. She left the Public Health Agency in 2014 and is currently an independent Board Member for Belfast Healthy Cities and chairs the Healthy Cities Working Group on Health Literacy.

Professor Adrian Edwards, Cardiff University

Professor Adrian Edwards is Professor in General Practice and Director of the Institute for Primary Care & Public Health at Cardiff University, Wales, UK. He is also a part-time general practitioner in Cwmbran, Gwent, South Wales and sees about 60 patients per week. He also has Visiting appointments at Aarhus and Southern Denmark Universities.

His main research interests are in risk communication and shared decision making. This has focused firstly on communication skills training for practitioners and evaluating this in practice as the practitioners consult with their own patients. More lately a specific focus is also on development and evaluation of decision aids. In 2009 he co-edited 'Shared Decision Making in Health Care: achieving evidence-based patient choice (Oxford University Press). Current interests also include the wide implementation of shared decision making approaches in the health care system, and supporting patients to self-manage long term conditions through enhanced Health Literacy approaches.

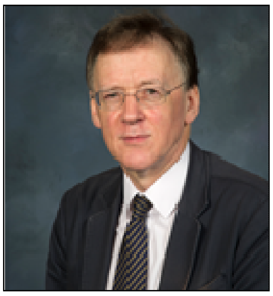
Professor Graham Watt, University of Glasgow

Professor Watt graduated at Aberdeen University in 1976 and, in a varied career, trained in general practice at Glyncorrwg in South Wales (where he worked with Dr Julian Tudor Hart), Ladywell Medical Centre in Edinburgh and Townhead Health Centre in Glasgow. He is accredited jointly in general practice and public health, and has held his current post at the University of Glasgow since 1994.

He has longstanding research interests in the epidemiology of health and disease in families, inequalities in health and health care and the development of academic capacity in primary care. In 2004, he gave the RCGP Pickles Lecture "General Practice and the Epidemiology of Health and Disease In Families" (BJGP 2005;54:939-44)

He was elected as a Fellow of the UK Academy of Medical Sciences in 2000, based mainly on epidemiological research studies, and as a Fellow of the Royal Society of Edinburgh in May 2014, based mainly on primary care research and advocacy.

He currently coordinates the Deep End Project, engaging with the 100 most deprived general practices in Scotland, and has written extensively on this subject (www.gla.ac.uk/deepend)



Dr Catherine Calderwood, Chief Medical Officer, Scotland

Catherine is the Chief Medical Officer for Scotland, appointed in March 2015.
She is an obstetrician and gynaecologist and continues to have a maternal medicine antenatal clinic at the Royal infirmary of Edinburgh.

Catherine qualified from Cambridge and Glasgow universities. As a junior doctor she worked in medical specialties in Glasgow Royal infirmary and at the Royal Infirmary of Edinburgh before completing her specialist training in obstetrics and gynaecology and maternal medicine in SE Scotland and St Thomas' Hospital London.

She became a medical adviser to Scottish Government in 2010 and has been instrumental in the work in reducing stillbirths and neonatal deaths in Scotland and in reducing avoidable harm in maternity services. More recently her role expanded and work includes major trauma services and the introduction of robotic surgery for prostate cancer to Scotland. Until her recent appointment as Chief Medical Officer Catherine was also the National Clinical Director for maternity and women's health for NHS England.

Her research interests include thromboembolic disease in pregnancy and she is an investigator on the AFFIRM study which will study the effect of the introduction of a standardized education and management plan for the care of women presenting with decreased fetal movements in hospitals throughout the UK and Ireland.
Catherine is chair of the UK maternal, newborn and infant Clinical Outcome Review Programme – the new process for confidential enquiries into maternal, newborn and infant deaths and severe morbidity run by MBRRACE-UK. She chairs the Scottish Government stillbirth working group and is a member of the RCOG stillbirth Clinical Studies Group. She was the obstetrician on the panel of the Morecambe Bay Inquiry into maternity and neonatal services and is a member of the recently formed Review of maternity and neonatal services in England.

Abstracts

Oral Presentations – Critical and Communicative Health Literacy

Understanding Health Research

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The idea: We have recently developed and launched an online interactive health literacy tool called Understanding Health Research. This MRC funded tool walks users through scientific concepts and processes so that interested people (including students, practitioners, and those looking for information on behalf of themselves or a loved one) can better understand and interpret health research studies. The tool has been designed to help non-scientists identify the strengths and weaknesses of a research article in order to assess the usefulness and validity of research findings for themselves. This session offers an overview of how we developed our tool and how it can be used with different audiences. We are also keen to better understand how the UHR tool can be of use to organizations in Scotland with an interest in health literacy.

Why it matters: Stories about health are a daily feature of life, telling us what is important and what risks we should be aware of. Critical health literacy is important for people if they are to exert greater control over their health, and yet we often find it difficult to assess the credibility of academic research we encounter through a variety of sources on a daily basis. This resource empowers users to evaluate scientific research papers for themselves, both teaching and reinforcing the basic critical appraisal skills that can contribute to health literacy.

Next steps: We aim to continue iteratively developing the tool, reaching new audiences and expanding its usefulness to different types of research. Ultimately, we also aim to develop a complementary add on to help users assess the quality of science based media stories.

Risks: Risks associated with the UHR tool include the risk of widening the digital divide by excluding non-internet users, and the risk that users may prefer or expect more certainty than scientific papers are generally able to provide on a given health topic. Steps have been taken to address these risks, as well as to manage user expectations. There is also the minor risk that authors may be aggrieved if the tool leads users to question the quality of their publications.

Critical health literacy as a capability: developing critical health literacy among migrant and ethnic minority groups

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The problem: Health literacy has gained momentum as a key concept for improving individual and population health outcomes but limited attention has been given to issues and barriers involved when promoting health literacy in marginalised population groups including migrant and minority ethnic groups. Adopting the same approaches to promoting health literacy skills as those used for the mainstream population may disadvantage and exclude groups who already have a problematic relationship with the health care system as well as low literacy levels, especially when inadequate knowledge of their levels of health literacy exists.

The approach: This paper will explore the value of conceptualising critical health literacy as an individual and community asset which promotes empowerment and critical consciousness, and will attempt to link critical health literacy to the capabilities approach literature which has gained momentum as a robust theoretical framework that addresses issues of social justice and health inequities. Findings from two research projects focusing on migrant groups in the Republic of Cyprus will be presented in order to explore ways in which critical health literacy in the context of a capabilities approach could be used to inform action on addressing the health needs of specific migrant groups.

Findings: Low levels of health literacy among transient migrant workers were found by the first study looking into migrants' experiences of health and health care in Cyprus. The project identified the importance to health of factors relating to migrants' levels of health literacy but these interacted with structural factors that impacted on their ability to remain healthy and deal with ill health. The capabilities approach framework was used to help understand the needs and interventions needed to promote all knowledge and skills that relate to all levels of health literacy in a way that addresses inequalities. The second project addressed issues of sexual violence among migrant female domestic workers and used participatory approaches to design and deliver a community education project aimed to improve women's knowledge of and skills in dealing with and preventing sexual violence. The project developed educational needs and outcomes through community involvement and included women and professionals in a train-the-trainers programme and this will be discussed within a critical health literacy model.

Consequences: Approaches that adopt an individualistic focus of health literacy with health literacy components specified in a top-down way will not be effective in addressing health inequalities among marginalised and vulnerable population groups. A model of critical health literacy has not been as extensively explored so far in the literature but this may be more effective in promoting long term positive health outcomes and addressing health inequalities. Critical health literacy is also very relevant to the capabilities approach that has issues of social justice at its core and has been used as a useful framework to guide policy development, policy and economic evaluation and intervention design within health and social care.

Communication and community health literacy in Dien Bien Province, Vietnam: a qualitative study

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The problem: Dien Bien Province (DBP) is a mountainous province of northwest Vietnam, predominantly populated by ethnic minority groups. Ethnic minorities in DBP experience higher levels of maternal and infant mortality compared to the national population. A previous maternal and child health project in DBP saw the development of a workable model for engaging the community as collaborative partners in ongoing health literacy programs. Feedback sought from community members indicated a need for appropriate community education to build community health literacy. Primary care professionals and community leaders were eager to work together, particularly in more remote areas where both groups felt that improved communication between health professionals and the community could have substantial benefits for health outcomes.

This study aims to explore how health professionals communicate health information to ethnic minority women during and after pregnancy, what factors impact upon this communication, how women understand and use that information in order to care for themselves and their children, and what other formal and informal sources of health information women access and trust.

The approach: Semi-structured interviews were conducted with health professionals (doctors, nurses, medical assistants, midwives, pharmacists) (n=22) at the primary care level in five communes of DBP, and focus groups were conducted with pregnant women and mothers of children under five years (n=37) belonging to the Thai and Hmong ethnic minorities in five villages. Interview and focus group data was analysed using a framework analysis method, with the analysis informed by field notes and observations from both Australian and Vietnamese researchers.

Findings: Health professionals at the primary care level identify poor communication and low patient knowledge as significant issues in their communities. Although health staff at this level often have strong ties to the communities that they work in, which fosters patient trust, health staff often find it difficult to communicate information about pregnancy, childbirth and reproductive health when there is discordance between patient and provider ethnicity, language, and level of education. Health staff use a variety of strategies to overcome these difficulties, but can find it difficult to conceive that communication problems may be due to their own lack of communication skills training and not simply a lack of a shared language. In focus groups, Thai and Hmong women said that they seek information about pregnancy and childbirth from a variety of sources, including the commune health staff, the District Hospital, television, radio, village health staff and older women in their communities, especially their mothers. Many women said that they do not understand a substantial amount of information that is provided to them about pregnancy and childbirth, and some reported that they do not feel that they are able to ask health staff questions. Others said that they were unable to follow health advice due to economic constraints.

Consequences: Health literacy in DBP may be improved through communication skills training for health staff, and through involving those networks where pregnant women and mothers source health information in future health literacy education, in order to strengthen the health literacy of the community as a whole.

Health literacy practices in a 3D social virtual world: A social model of health literacy

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The problem: Social Virtual Worlds (VWs) are online 3D multiuser virtual environments (MUVE). Access by users or 'residents' of VWs is through the creation of a representation of themselves, known as an avatar. Recently these social networking tools have been used to present health information using interactive games, simulations, peer support groups and healthcare seminars. However, no published studies have investigated the health literacy skills and practices undertaken by individuals or communities in virtual worlds. Therefore, this study aimed to advance understanding of the social skills and health literacy practices used by individuals and communities within VWs and the influence on physical world health behaviour.

The approach: Twenty five semi-structured interviews were conducted with participants within the virtual world Second Life from September 2011 – June 2012. Thematic analysis was used to analyse the data.

Findings: The findings demonstrated that participants used their social VW networks to search for, access, experience, appraise, understand, and make decisions to use health information. These social methods allowed reciprocal sharing of information and access to people within multiple VW groups who had different VW knowledge, skills, and health literacy practices. This maximised the health literacy resources available, meaning improvements to individual or group health literacy was not reliant on individuals' skills but on social connections and collective health literacy practices.

Consequences: Definitions, models and measurements of health literacy predominantly position 'health literacy' as a set of skills residing within the individual. Such assumptions, however, ignore the social processes, resources, interactions and practices inherent within developing health literacy, explicitly identified in this study. An adapted framework of social skills and cultural literacy competencies used within VWs to improve individual and community health literacy will be presented. This is the first collection of social skills and adult health literacies used within VWs and make a unique contribution to increasing the understanding of the type of literacies used in social VWs and social networks to access, appraise understand, and use health information.

Oral Presentations – Health Literacy and the Healthcare Workforce

Building workforce capability for health literacy

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The idea: 'Making it Easy: a health literacy action plan for Scotland' (Scottish Government, 2014) aims to enable Scotland to be a health literate society. The Knowledge Services Group, NHS Education for Scotland are responsible for the following actions from the plan:

- The development of The Health Literacy Place Website www.healthliteracyplace.org.uk
- Building workforce capability for health literacy.

A number of complimentary activities are being undertaken which support each other to offer a coherent package of support for health and social care staff in terms of health literacy.

The Health Literacy Place launched in October 2015 as part of Health Literacy Month. This website is the 'go to' place for health literacy information and support in Scotland. The website provides tools, learning and evidence for health and social care staff and opportunities to share practice through news, blogs and case studies. People Connect is an online web tool available via the Knowledge Network in Scotland, this is being used to identify and join up people interested in health literacy. To raise awareness of the website and wider health literacy messages, supporting materials and a Twitter account have been developed.

To achieve the spread of health literacy knowledge and innovation at a local level a supporter role has been developed, at October 2015 a total of 25 supporters are signed up across the 14 NHS Board areas in Scotland.
We are developing a programme of health literacy awareness raising sessions across Scotland for both supporters and other health and social care staff. Many staff groups have already requested health literacy input to training/conferences and sessions have been delivered to groups including Resource Officers, Practice Nurses, GPs and Public Health.
An outcome and evaluation framework has been developed, informed by knowledge into action principles (NHS Scotland, 2012).

Why it matters: This work contributes to the national action plan for health literacy in Scotland as well as policy documents including The Healthcare Quality Strategy for Scotland (Scottish Government, 2010). Health literacy fits with national priority areas such as person-centred, patient safety and reducing health inequalities.
The health and social care workforce in Scotland are in a prime position to promote and support health literacy. While further activity is taking place to raise awareness with the public this area of activity focuses on the role of staff.

Next steps: The Health Literacy Place and supporter network continues to grow and people are being encouraged to become more involved through blogs and discussions to share experiences and ideas. A training programme to raise awareness of health literacy with supporters and others with an interest will be rolled out in addition to continuing input to sessions for specific disciplines.
The outcome and evaluation framework for the programme and undertaking activities to support the evaluation will be further developed and implemented.

Risks:

- Lack of interest from professionals – based on work so far and interest this is gathering momentum
- Evidencing the impact of the activities – robust evaluation framework is in place.

Healthcare providers' views about how to develop health literacy in an older adult population

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The problem: Health literacy describes the ability of individuals to access, understand and use information to benefit their health. Lower health literacy levels are associated with increased mortality and morbidity, and are especially prevalent in older adult populations. UK NHS policy recognises the importance of meaningful patient engagement in health care decisions. For many older adults vital health information is often inaccessible, and they are not sufficiently supported by their health care provider to engage meaningfully in decisions about their health care. This presentation explores healthcare providers' perceptions about health literacy in order to better understand the facilitators and barriers to improving patient health literacy within clinical practice. The research reported here examines healthcare providers' views about recommended health literacy strategies with older adult populations with varying health literacy levels.

The approach: Purposive sampling was used to recruit 22 NHS healthcare providers working with older adults in one community NHS Trust. Focus groups consisted of multidisciplinary teams, from pulmonary rehabilitation, palliative care, chronic fatigue, neurological and persistent pain services. Four focus groups were conducted using a topic guide structured around an established health literacy framework describing functional, interactive and critical health literacy. The topics explored in the focus groups included use of health literacy screening tools and/or universal precautions to communication, and communication techniques designed to improve health literacy. Examples of health literacy screening tools were used to facilitate discussions. The focus groups were audio-recorded and the verbatim transcripts were interrogated using a framework approach.

Findings: Analysis revealed low knowledge and awareness about health literacy; uncertainty about identifying older adults' health literacy levels; and concerns about using health literacy screening tools and universal precautions. By contrast, participants placed emphasis on relationship and trust building, and tailoring interactions to older adults' individual health literacy needs, as well as facilitators and barriers to the integration of and development of health literacy in clinical practice.

Consequences: Healthcare providers have concerns about the use of both health literacy screening tools and universal precautions, citing the potential to cause shame and damage their relationships with their older adult patients. Instead, they emphasised the importance of tailoring interactions to older adults' health literacy needs. Despite this, health care providers lacked knowledge and awareness about how to identify older adults' health literacy levels and develop their health literacy abilities. If older adults are to be engaged meaningfully in decisions about their health, healthcare providers need support to develop their knowledge and skills to communicate effectively with older adults and to support the development of older adults' abilities in accessing, understanding and using health information. Further research is also warranted to ascertain the acceptability and utility of using health literacy screening and universal precautions with older adult patients, from both patient and providers' perspectives.

Improving numeracy among NHS support workers and attitudes to learning across Trusts

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The problem: Support workers in the NHS are being given increasing responsibility over patient observations and medications. Numeracy is essential for ensuring that these patient needs can be picked up quickly and effectively. Understanding how different variables such as heart rate and blood pressure interrelate, using unfamiliar scales and under the pressure of time requires support workers to have strong confidence and competence in their numeracy skills. However, due to low numeracy levels in the UK, where only 22% of adults are working at Level 2 Numeracy, Trusts are finding it difficult to ensure staff have the necessary skills.

Support workers are also the staff who spend the most time with patients, so get more time to communicate with and listen to their concerns. Having good numeracy skills is essential in being able to communicate complex information to patients. Whilst Talent for Care has started to address the training needs of HCAs, anxieties around numeracy have prevented this campaign from engaging specifically around numeracy.

The approach: Understanding people's numerate behaviours requires an in-depth understanding of how their work, family, and home environments have shaped their attitudes around maths. Therefore we took a qualitative approach, triangulating analysis from focus groups, observations, and informal conversations. Seven focus groups with support workers, in three Trusts, asked staff about their experiences and attitudes around numeracy. Observations of training, the use of numeracy on wards, and conversations with Learning & Development teams, Union Learning Reps, and key national stakeholders provided an organisational perspective on support worker's development.

Findings: Findings suggested that policies encouraging HCAs to improve their skills are not yet being practiced on the ground. Many HCAs felt that the Trust's training opportunities were aimed primary at Band 5s or above – they are the "bottom of the ladder". This view persisted even in Trusts where opportunities were available, suggesting team leaders were not always aware of the opportunities available or the need for HCAs to take them up. Many team leaders and HCAs were unaware of the importance of numeracy for the HCA job role, or lacked the belief that they would be able to improve their numeracy skills. This was often perpetuated by negative experiences of numeracy at school, where people experienced boredom, being told they can't do maths, or being sent to the back of the class; indeed it seemed that being forced to the bottom of an entrenched hierarchy was an occurrence throughout their experiences of work and education. However, there were some HCAs who were more confident about their numeracy skills and had experienced more positive attitudes around learning throughout their lives.

The consequences: This research suggests that more work needs to be done to ensure HCAs, team leaders, and managers understand the importance of numeracy for the HCA role. It is also critical that future strategies to improve numeracy address the confidence of HCAs and attitudes around numeracy. It is only through changing values and beliefs that related issues around monitoring, care and communication with patients can be addressed.

Nurses' perceptions of health literacy in adolescent patients: A qualitative descriptive study

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The problem: Worldwide, adolescents struggle with a variety of health problems (e.g., sexually transmitted infections, mental health problems, alcohol and substance abuse, chronic diseases such as diabetes, etc.) for which they may not seek, nor receive, adequate treatment. While the promotion of health literacy has been identified as one way to prevent negative health outcomes in adolescents, and prepare adolescents to be active participants in their care, there is a scarcity of research on how adolescent health literacy is both perceived, and promoted, by health care providers. To address this gap, we sought to answer: What are public health nurses' perceptions of health literacy in adolescent patients and related communication practices with adolescent patients?

The approach: We adopted the qualitative descriptive approach described by Sandelowski (2010; 2000). Semi-structured interviews were conducted with a purposeful sample (n = 9) of public health nurses providing care to adolescent patients in one of five health authorities located in British Columbia, Canada. Content analysis was used to identify themes emerging from the data. Emerging themes were confirmed by two health literacy researchers and a public health nurse possessing in-depth knowledge of the context, but not involved in the collection of the data.

Findings: Nurses ascribed multiple and differing meanings to the term health literacy, the most common being an understanding of one's health or health-related information. Most nurses provided various types of health information to adolescents, used more than one mode of communication (i.e., verbal and written), and assessed adolescents' understanding primarily by asking a series of questions. Innovative approaches used by nurses to provide health information to adolescent patients included the provision of services in schools; training peer educators to go into schools; providing business cards with information on where to seek more information (more acceptable than larger printed information); and the use of text messaging. These approaches, however, were not uniformly adopted and some nurses expressed concerns about the lack of security associated with the use of text messaging.

Nurses identified both patient- and provider-related barriers to effective communication with adolescent patients. Anxiety/fear in adolescents emerged as a prominent patient-related barrier (e.g., fear of family finding out, fear of unknown, fear of disclosure, fear of asking questions) as did adolescents' lack of understanding about confidentiality policies. Provider-related barriers included negative attitudes toward adolescents, lack of accessibility (e.g., poor service hours and location difficult to access), and inability to respond to text messages from adolescent patients in a timely manner. All of the nurses interviewed in our study expressed an interest in learning more about health literacy as it pertains to adolescents and preferred workshops, oral presentations, and webinars over other modes of learning.

Consequences: Without attention to the patient and provider barriers identified in this study, efforts to promote health literacy in adolescent patients will be limited. Innovations that increase adolescents' timely access to health information and services, and do not put adolescents at risk for breach of privacy, should be accelerated (e.g., use of peer educators in schools, nurses in schools).

Oral Presentations – Health Literacy, Mental and Physical Health

Older People, Mental Health and Wellbeing: A Mixed Methods Study

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The problem: Improving mental health across the life course and into older age is a Government priority. Depression affects many older adults however it is under-recognised and under-treated. Mental health literacy (MHL) is knowledge and beliefs about mental disorders which aid their recognition, management or prevention. Improving MHL could improve recognition of depressive symptoms, increase help-seeking behaviour and access to mental health services. To date little UK research has been done on MHL and older people.

The approach: This exploratory study aims to:
1. Review existing literature on views of MHL and older people
2. Measure HL and MHL levels in a sample of older adults
3. Test the feasibility of using HL and MHL measures with older adults
4. Explore the views of older adults and of primary care health professionals about MHL (specifically the recognition of depressive symptoms, management and prevention of depression including help-seeking behaviour and access to mental health services)

This is a 3-phase mixed methods study.

Phase 1: We searched five databases for empirical qualitative MHL studies (1970-2014). Study quality was assessed using the CASP Qualitative Research Checklist. Following extraction the data were synthesised using thematic synthesis.
Phase 2: 374 people (52% response) from the cohort of a previous study "The Collaborative Care in Screen-Positive Elders (CASPER) study", aged 65 years and above completed a postal questionnaire to assess their HL and MHL levels using validated measures. Descriptive statistics were undertaken to explore HL and MHL levels by gender and age (>65, >75) and completion rates of the HL and MHL measures to assess feasibility of completion within this population.
Phase 3: 16 Phase 2 participants and 2 nurses were interviewed to explore views about MHL in older people (patient and practitioner experiences). Data are being analysed using thematic analysis. NVivo is facilitating data handling.
Once independently analysed, the data from all three phases will then be synthesised using a triangulation protocol.

Findings:
Phase 1: Only two studies that explored MHL in older people were identified. One was of Hmong elders in the US and one was of older African Americans. Key barriers to accessing mental health services were cultural beliefs about mental health (fear of stigma), language, and a lack of understanding, trust and awareness of services.
Phase 2: To date, analysis (n=366) of the HL data has revealed that mean scores were similar across all domains of the HL Questionnaire ranging from 2.6 to 2.9 (out of 4) and 3.8 to 4.1 (out of 5) indicating that participants had reasonable levels of health literacy. There were no significant differences across age groups and gender.
Analysis of the Phase 2 MHL data and Phase 3 data; and the mixed method synthesis will be completed by January 2016.

Consequences: NHS England and Royal College of General Practitioners recently launched a 5-year action plan to address challenges created by low MHL. This exploratory study will begin to develop understanding of this poorly researched, yet rapidly emerging area.

Health Literacy in a young offender prison population

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The problem: There are approximately 85,000 people in prisons in England and Wales, presenting with a high prevalence of complex health needs including mental health issues, chronic health conditions, substance abuse and communicable diseases. Young adult men (defined as age 18 – 20 years) are often the most vulnerable, with increased health needs and histories of violence, abuse and neglect, and time spent in local authority care. Although the primary aim of incarceration is not health improvement, prisons provide an opportunity for health services to access a hard-to-reach and underserved population. For many offenders, prison is the first time that they consider their health needs and make contact with health services. As such, there has been increasing political commitment to promote health in prison, however, there have been relatively few studies which have addressed the tensions which exist in promoting health in a prison setting. Specifically, prisons have values, rules, and rituals that enable prisoners to be observed, contained, and disempowered; these are at odds with any notion that prisoners can be encouraged to take charge of their health. This research therefore aimed to explore health literacy in a prison setting.

The approach: The Newest Vital Sign (NVS), Rapid Estimate of Adult Literacy in Medicine (REALM) and the European Health Literacy Survey questionnaire (HLS-EU-Q) were administered as a structured interview to young adult men in a single young offender institution. Additional quantitative measures of health and wellbeing and behaviours (Hospital Anxiety and Depression Scale [HADS], Scale of Positive and Negative Experience [SPANE], Patient Health Questionnaire [PHQ-15], Global Adult Tobacco Scale [GATS]) were also administered

Findings: 30% (n=125) of the prison population completed the structured interview. 50% (REALM) and 74% (NVS) had limited health literacy. 77% had low health literacy on the HLS-EU-Q with the greatest difficulties in access to health information and services. Low health literacy across all the scales were related to increased anxiety and depression scores (HADS) and negative affect (SPANE) and intentions to quit smoking. Health Literacy was not related to age, ethnicity or nationality.

Consequences: This research demonstrates that young adults in prison represent a disadvantaged group with low health literacy. The research highlights particular structural challenges for people in prison in developing health literacy and makes recommendations for the promotion of a health literate prison setting.

Investigating the impact of health literacy in individuals with chronic pain

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The problem: Inadequate health literacy (HL) - a person's ability to find, understand and utilise information effectively to make informed decisions about their health, has been linked to poorer health outcomes in a number of chronic diseases. Although inadequate HL scores have been established in Ireland at 40%, the impact of HL in those with chronic pain is unknown. Given the high cost of chronic pain to the health service, this study aims to establish if HL is linked to poorer outcomes and behaviours in patients with chronic pain.

The approach: A cross-sectional questionnaire was distributed in three pain clinics, in university hospitals in Dublin, Ireland. Those eligible for inclusion were over 18 years old, a new referral to the pain clinic, had pain lasting longer than three months, and had no cognitive deficits or active psychiatric illnesses. The questionnaire comprised the following assessments: a demographic section (gender, age, educational attainment, and socioeconomic status), chronic pain status (duration and severity, disease-related knowledge, and efficacy of management strategies), quality of life (SF-36), beliefs about pain control (BPCQ), and a validated HL measurement tool (Newest Vital Sign).

Findings: Of the 131 participants that were recruited, 54.2% had inadequate HL, and the group was subsequently stratified according to HL level (i.e. inadequate or adequate). In bivariate analysis, inadequate HL was associated with older age ($p<0.001$), being unemployed or retired ($p=0.005$), poorer educational attainment ($P<0.001$), lower income, increased presence of comorbidities ($p=0.038$), and being less likely to use hospital (non-emergency) or allied health services ($p=0.001$). In contrast, adequate HL associated with increased disease-related knowledge ($p=0.002$), and more appropriate beliefs about pain ($p<0.05$). However, in multivariate analysis, only disease-related knowledge (OR 2.5, 95%CI 1.0—6.3) and beliefs about pain (B=-2.317, 95%CI -4.2—-0.5) remained independently associated with HL.

Consequences: Inadequate HL is prevalent in chronic pain patients, and may impact on the development of important health behaviours that are necessary for managing their condition. Healthcare professionals managing this patient cohort should consider including HL-sensitive strategies, such as Plain English or 'Teach-Back Methods' in their practice, to ensure optimal delivery of treatment. More research is needed to understand the mediating influence of HL on health outcomes in chronic pain patients.

Health Literacy and Diabetes Management among South Asians in the UK: A Photovoice Study

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The problem: 'Health literacy entails people's knowledge, motivation and competencies to access, understand, appraise, and apply health care information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during life course' (Sorensen et al. 2012- p,3). Poor health literacy is common among racial and ethnic minorities, elderly persons, and patients with chronic conditions (Schillinger et al, 2002). Alarmingly, South Asians in the U.K are up to six times more likely to have diabetes than the white population (Diabetes UK, 2012). In the first phase of this project it was found that people belonging to South Asian community have limited health literacy levels that may have particular effect on diabetes management, as it is a complex condition requiring poly-pharmacy, regular review, behaviour modification and the development of self-management skills (Department of Health, 2001). Present research using collaborative research approach that provides an opportunity to equitably involve South Asians in research process and recognise the unique strengths and concerns of this community related to diabetes management and health literacy needs. In this case PAR is utilised with the aim of combing knowledge and action of social change to improve community health and reduce health disparities.

The approach: The data collection method used in this study is a Photovoice exercise (Wang, et.al, 1998) to enrich the participatory element of this research by engaging the intended community in this research. Participatory action research (PAR) is characterised by collaborative investigation, reflection and action. A PAR framework was employed aiming to empower and engage South Asians with diabetes, facilitating them to research, and reflect upon how they are managing their condition. The photovoice method uses cameras s a research tool to engage and empower the targeted population. 11 South Asians (3 females and 8 Male) took part in 5 photvoce workshops. Participants took photographs, communicating how they are managing their diabetes along with emphasizing their cultural perspective and health literacy needs. These were discussed and subject to participant-led thematic analysis. Further Interpretative phenomenological analysis will be used in participants' photographs, SHOWED narratives and workshop discussions.

Findings: Preliminary analysis suggests that food and physical activity two major variables deeply rooted in South Asian cultural practices and further language barrier is considered another obstacle in utilizing the healthcare services effectively, complete results will be ready in January 2016.

Consequences: These findings may be used to promote a user led understanding of experience of managing diabetes and health literacy needs of the South Asians in the UK. Outcomes from this project will be an excellent opportunity for building community capacity and then facilitating their ability to address these issues with other community members and appropriate policy makers.

Oral Presentations – Co-creating Health and Health Literacy

Developing a film about cervical screening for Black and Minority Ethnic (BME) women with low health literacy

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The idea: Co-create, with BME women with lower levels of Health Literacy, the content for an educational film to encourage women from those communities to have a smear test

Why it matters: Every day eight women are diagnosed with cervical cancer and three die from the disease. It is largely preventable, yet 22.2% of UK women do not take up their screening invitation. Research shows that

43%/61% of adults (18-65) do not have adequate health literacy skills respectively to understand health information (Rowlands et al 2015). Ethnicity is associated with lower health literacy.

Awareness of cervical cancer and prevention is lower amongst women from BME backgrounds. Different perceptions and barriers to screening are experienced and some communities do not recognise the term ‘cervical screening’ or ‘smear test’ (Marlow et al 2015). Barriers to attendance include emotional (fear, embarrassment, shame) and considering themselves as low risk. A third more BME women of screening age (12%) compared to white women (8%) said they had never attended screening. 30% of Asian women didn’t know what cervical screening is. These could all be described as Health Literacy issues.

‘Your Guide to Cervical Screening (smear test)’ is a collaborative educational film which offers another way for BME women with lower levels of Health Literacy to gain information about cervical screening, covering what will happen during the test and how the test can help to prevent cancer. The CHLF recruited focus groups of ethnic minority women with lower health literacy. The focus groups provided feedback at the initial ideas phase helping JCCT to choose the type of resource and content, again at the first storyboard stage and finally at a first film edit. At the latter two stages CHLF checked very closely that the women could understand the messages the film was conveying. Their views crafted the resource alongside a group made up of experts in screening. The film, available on YouTube features real women from different ethnic backgrounds alongside animations to clearly explain the process and what to expect at screening.

We believe that this may be the first time that a health education film has been co-created and co-produced this way and that it offers an innovative future best practice model.

Next steps: Working with our networks to disseminate the film over the coming year and promoting it via local, specialist and national media and engagement with the general public, community groups, ESOL learners, CCGs and primary care professionals. We will translate it into other languages and produce a DVD resource that can be used offline. Evaluation will be conducted to understand the impact and consider its role in screening uptake

Risks: The film may be too broad and we may need to consider how we ensure specific communities engage with it. It will be hard to identify its direct impact on screening uptake.

HEY! (Healthy Eating for Young Children)

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The idea: To co-create, with Danone Nutricia Early Life Nutrition, an Early Years Health Literacy intervention which aims to improve the health outcomes and life chances of children aged 1-3 by engaging their parents in healthy eating and learning.

Why it matters: The World Health Organisation (WHO) regards childhood obesity as one of the most serious global public health challenges for the 21st century. Obese children are at an increased risk of developing various health problems, and are more likely to become obese adults. Data from the Health Survey for England (HSE) from 2012 shows that around 28% of children aged 2 to 15 were classed as either overweight or obese. Recent studies suggest that environmental factors in the very earliest stages of life, the first 1000 days from conception to a child’s second birthday, are more influential than genetics in determining long term health outcomes – including growth and development and the risk of obesity, diabetes, heart problems and food allergies. And for parents, one of the factors they can influence is nutrition (James Murdoch www.mini-kin.com Spring 2015).

HEY! is based on a body of evidence that shows that childhood obesity is linked to parents’ eating habits. Recent research by the University of Exeter published in the International Journal of Obesity in April 2015 discovered that the rise in obesity among very young children has been largely restricted to the minority with obese parents. The research data suggests that “parenting is the fundamental influence on weight gain in the early years, whereas more general (peer group) influences take over later on…and public health strategies may need to be tailored accordingly”.

Research demonstrates that families living in the most disadvantaged communities are often those who have the worst health outcomes because they face the most challenges in managing their health and wellbeing. According to Rowlands et al (2015) 43%/61% of working age adults in England (18-65) routinely do not understand health information. These Health Literacy challenges are compounded by low levels of general language, literacy and numeracy.

For this reason, HEY! took an embedded learning approach by delivering health messages with skills for life (basic skills) learning embedded within them. This is what is unique about HEY!: its focus on improving Health Literacy levels, rather than simply providing information.

Next steps: HEY! is being rolled out across England through a Train the Trainer and Grants programme. Early Years staff members are provided with free training and resources to deliver HEY! to parents and toddlers in their local area and grants are provided to support delivery for the first year. The programme has recently been externally evaluated and concluded that “...the Danone HEY! course is having a significant and sustained impact on healthy eating and healthy lifestyles for parents and their young children. This impact is largely due to the design of HEY! and the resources in place for the delivery of HEY!...”

Risks: Offering courses through Early Years settings such as Children’s Centres may still miss some of the most vulnerable and socially deprived parents targeted. In addition, Children’s Centres and other early year settings are being re-organised and closed which makes it hard to engage staff.

What patient and public involvement is there in research on health literacy: A descriptive critical review

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The problem: Health literacy effects health status more than any demographic factor. Differences in health literacy impact on whether people use preventive measures or self-manage effectively, which further affects future health outcomes. However, interventions to improve health literacy often fail to look at patient oriented outcomes and make only modest differences to knowledge, behaviour or health. With emphasis now focused on patient-centred care (PCC) we consider whether health literacy interventions for older people are ‘patient centred’, who is involved in the process and how these effect knowledge, behaviour and health outcomes.

The approach: We do this by looking for reported evidence of involvement of patients, public, professional and stakeholders in both the research process and the care production in a sub-category of studies from an existing inventory of the Intervention Research on Health Literacy in the Ageing Population (IROHLA) study. The search strategy included nominally successfully implemented health literacy interventions (“health literacy” phrase is in the title or abstract) on older adults (50+ years) in the health sector 2003 –2013 inclusive. We assessed PCC by who drives the research agenda, whether it is organisational or patient led and how much patients, public, professionals or stakeholders contribute to the research. We analysed the studies into areas of patient and public involvement (PPI) broadly based on the model developed by the NIHR.

Findings: Of 94 studies that met initial criteria stated, none referred to PPI as a formal process and 72 studies did not seek input from others outside the immediate research team. Patient, public, professional and stakeholder involvement was found in three areas of research: design, management and evaluation. Involvement included volunteers, older people, professionals, patients, community groups, and ethnic minority groups. All studies were driven by an organisational and biomedical agenda, and PCC varied greatly between studies. Overall, 13 studies showed significant results for knowledge, behavioural or health outcomes, of which nine were patient centred. There are indications these might improve or undermine health literacy interventions in other ways.

Consequences: Focusing on organisational-led research may not fully address the health literacy needs of people in real world situations. Inclusion of patient, public, professional and stakeholder involvement (PPPSI) is needed early in the research planning and should be patient centred. Despite the drive for PPI and PCC in research and healthcare implementation of these concepts is muddled and further compounded by poor reporting and little evaluation of the impact of these on the research process and outcomes. However, unexpected benefits and negative outcomes that do not fit an organisational framework have potential to improve health literacy by changing knowledge, skills and behaviour to improve health outcomes in individuals or communities.

Supporting the public's health literacy by delivering services through community pharmacies – A Pilot project

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The context: Community pharmacies (CP) provide accessible information and advice concerning prescribed medicines, self-care, lifestyle and behavioural aspects of health care to the general public. For many people CP are their first point of contact with any health or social care professionals and the pharmacy acts as a 'hub', offering support and referring onto to others where appropriate.
Some people who take regular medicines are unable to physically access the pharmacy and rely upon a collection/ delivery service for their prescribed medicines. These patients tend to be elderly, often living alone and have limited mobility and interaction with others. This group of the population are restricted in their opportunity to receive advice and support from health care professionals, furthermore, we have evidence from previous work in Stoke, this is the segment of our local population who are most likely to struggle with their health literacy.

The idea: We have developed a service which utilises the skills of Pharmacy technicians to deliver a domiciliary pharmacy support service for patients who regularly receive their medicines via a collection and delivery service. The pharmacy technicians, will, with agreement from the patients, visit their homes and have a discussion with the patient about their medicines, their general health and their lifestyle along with their understanding of health information. The pharmacy technicians will offer whatever support is within their competence and refer the patients to other local statutory and voluntary services where appropriate.

Why it matters: A lack of opportunity to interface with CP services could be one of the risk factors associated with having low health literacy which will impact on the health benefits patients receive even if they are receiving regular prescribed medicines. By providing an opportunity for this interaction health literacy may be improved. It will not only be through the one to one consultation with the pharmacy technician, but also through any additional interactions that occur if patients are referred onto other on-going services where needs are identified.

Next steps: This project has currently now finished and ready to be evaluated. The analysis will be via Keele University and is on track to be finished in January 2016. The evaluation is to identify if this group of the population are those with low health literacy and if this intervention supports their health literacy needs. The patient visits will begin in April 2014 with the aim of completing number of visits by Oct 2015. Further to this project there will be a roll out of training to target all pharmacists and their support staff. The training will consist of understanding health literacy, how the CP can identify patients with limited health literacy and what pharmacy can change in their day to day practice to help these patients.

Risks: The success of this project will depend on the skills of the pharmacy technicians to identify patients who have poor health literacy and then to offer support that will improve health literacy. Training and on-going support from the project team will be offered and evaluated as part of the overall project.

Oral Presentations –Health Literacy and Intellectual Disabilities

What makes information accessible within healthcare settings: insights from a learning disability context

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The problem: People with a learning disability experience a range of health inequalities, partly stemming from barriers in their access to health information and healthcare. Increased inclusion in healthcare decision making, supported by improvements in health literacy, is essential in addressing inequalities. This study explored the role of accessible information (AI) in promoting health literacy among people with a learning disability as a starting point to consider the issue in relation to other client groups

The approach: Experiences of a range of stakeholders (people with a learning disability, carers, and staff from Learning Disability, Adult Mental Health, Child and Adolescent Mental Health and Primary Care services) were gathered via quantitative and qualitative methods, and used to build a contemporary snap shot of current practices concerning AI within the NHS. An on-line questionnaire for clinicians (102 respondents) examined the range of AI resources used, perceptions of AI, and involvement in the production of AI, and was quantitatively analysed. Focus groups for clinicians (35 participants) and semi-structured interviews (10 with carers, 10 with people with learning disabilities) tapped information seeking behaviour and the use of AI to support inclusion and healthcare decision making, and were thematically analysed.

Findings: Data from interviews, focus groups, and questionnaires echoed elements of the current evidence base, especially the importance of conceptualising information provision from a ‘process’ perspective, not only a ‘resource’ one). Questionnaire data demonstrated variable use and understanding of AI, and correlations between knowledge of AI and views regarding its relevance. Interview and focus group data highlighted the importance of taking a person-centred approach to information provision as a way to help facilitate clients’ understanding and engagement and how materials were often adapted to meet individual needs.. Carers discussed how they support clients in understanding health information and called for increased recognition of their contribution. The contribution of clinicians out-with the Learning Disability Service highlighted the relevance of easy-read information for a broad range of client groups.

Consequences: Providing information to meet the specific needs of the individual was a prominent theme for staff, carers and people with learning disabilities. However, the results also highlighted the potential for accessible information to support empowering partnerships with service users more generally, through the broader promotion of accessible information, as a means of addressing service-created inequalities. AI is traditionally regarded as a niche resource, particularly relevant within learning disability services, however it has relevance as a general model for information provision to all, particularly were it to be better informed by other existing areas of knowledge regarding cognition and design than it has perhaps been to date.

Developing an action plan which improves access to health information and addresses health literacy

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The idea: The Health Information & Resources Service, Department of Public Health, NHS Ayrshire & Arran, provides quality assured information and resource materials which promote health and wellbeing, prevent illness, or minimise deterioration of conditions.

Because we know the provision of information alone is not sufficient and that a range of skills are needed in order to understand and act on information, have considered what actions can be taken to ensure people have the skills to act on health information and use this to prevent ill health and improve health and wellbeing.

A new three year action plan is being developed for the Health Information & Resources Service and is underpinned by actions to improve health literacy. This has involved us reviewing the current evidence as well as engaging with stakeholders to get their views on this.
Some of these actions will involve reviewing existing work which has been delivered (for example, reviewing our health literacy training) and new actions (for example, developing a project to address health literacy within a specific population group).

The action plan has recently undergone a period of consultation, and is currently being finalised for implementation in partnership with a range of agencies.

Why it matters: The action plan is focussing on actions specifically at groups/populations at risk of lower health literacy. This means that actions should improve health literacy thus improving health and reducing health inequalities.

A logic model has been created to show the short, medium and long term outcomes or changes we expect to see as a result of these actions being implemented – this shows that this work matters as the long term outcomes include our population having improved health and wellbeing.

Next steps: The action plan will be finalised by the end of December 2015. A new steering group, consisting of a range of partners, will be set up in 2016 to oversee implementation of the action plan.

Specific actions within the plan will be progressed – this will include:
- Reviewing health literacy training by end of March 2016
- Developing a project to address health literacy over the business year of 2016

Risks:
- Capacity of the team/service to take forward implementation of the action plan.
- Partners may not engage with us regarding implementation of the action plan due to competing pressures.
- Whilst our approach is focusing on actions to improve health and is intending on being more upstream, there is a risk that partners priorities focus of actions to address health literacy targeting those with specific health conditions.

The Easy Read Project. Comprehension of ‘easy read’ health-related text by people with intellectual disabilities

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The problem: Health material designated as ‘easy read’ produced for people with intellectual disabilities (IDs) often plays a pivotal role within functional and communicative aspects of health literacy. However, there is no evidence that simplified text and literacy mediation (e.g. verbal explanation) makes a difference to the understanding of health information. Failure to understand health information for people with IDs can perpetuate inequalities in resourcing effective care.

The approach: In this study, a quasi-experimental 2X2 between subjects factorial design was used to test the effect of linguistically simplified text (functional) and literacy mediation (communicative) on the construction of meaning from ‘easy read’ health related information. Sixty adults with IDs undertook The Easy Read Task, each allocated to one of four conditions (with and without simplified language/ with and without mediation). The study aimed to answer the question: What effect does linguistic complexity and literacy mediation have on the reading comprehension of 'easy read' information by people with IDs. Analyses of variance (ANOVA) were conducted on the data, testing for main effects of linguistic complexity and mediation on comprehension.

Findings: Results showed that neither linguistic complexity of the text nor mediation independently or combined made a significant difference to the understanding of information. However, when receptive vocabulary was controlled using analysis of covariance (ANCOVA), a significant interaction was present between the factors of simplified text and mediation.

Consequences: This suggests that for effective understanding of written material about health, attention needs to extend beyond a consideration of form (as found in 'easy read' documents) and the delivery of information, to address a better understanding of individual capacity for language processing.

Workshops

Health literacy in Scotland – sharing our learning and ideas

L Murphy, K Burton, P Easton

NHS Education for Scotland

What we will do:

- Describe how the national action plan is being put into action across Scotland
- Discuss how you can join in and apply this learning in your own area

Following an introductory overview of health literacy in Scotland you will have 15 minutes with each of the following groups to hear more detail about key aspects of improving health literacy in Scotland and how you can use these ideas and learning in your own organisation/area:

1. Resources
2. Workforce development and capability building
3. The national demonstrator

Health Literacy within current practice: applying essential criteria

B McKullen, A McCusker

Belfast Healthy Cities Project, A World Health Organization Healthy City, Secretariat for WHO European Healthy Cities Networks

Health Literacy is a core theme for Belfast as a member of the WHO Healthy Cities Network Phase VI (2014-2018). The benefits of improved health literacy are felt across society and between government departments, highlighted locally within the Northern Ireland Executive's strategic framework for public health, Making Life Better and through a number of initiatives occurring at local and regional level.

This workshop will outline the approach of the cross-sectoral health literacy working group in Belfast to establish health literacy within policy and practice. Considered a relatively new concept in Belfast, a set of essential and desirable criteria were developed to clearly identify elements of health literacy within current policy and practice.

The aims of the workshop will be to:

1. Share how the criteria were developed and what they are
2. Make the information relevant to the participants by asking them to apply the criteria to a case study and decide is the case study contributes to Health Literacy
3. Identify if there are any other criteria which might be used
4. Explore opportunities to apply the criteria in their own workplace and other settings

Ophelia

Chair: Sue Roberts[2]**,** Chair of Year of Care Partnerships, Northumbria Healthcare Foundation Trust
Panellists: Jess Svetz[1]**, Simon Eaton** [2]**, Blythe Robertson** [3]**, Alison Beauchamp** [4]**, Richard Osbourne** [5]
[1] Head of Quality and Service Improvement, Hywel Dda University Health Board, “Transforming Chronic Pain services in Hywel Dda University Health Board using Ophelia”
[2] Clinical Lead of Year of Care Partnerships, Northumbria Healthcare Foundation Trust, “North East of England Ophelia Experience”
[3] Policy Lead for Self-Management and Health Literacy, Scottish Government “Using Ophelia to build community enablement in Letham, Tayside”
[4], Senior Research Fellow, Deakin University
International Ophelia:
[5]**,**Professor and Chair in Public Health, School of Health and Social Development Centre for Population Health Research, Faculty of Health, Deakin University

Ophelia (OPtimising Health LIterAcy) is a process developed by Prof Richard Osborne and his team from Deakin University, Melbourne. It aims to evaluate the health literacy needs of a group or population using the Health Literacy Questionnaire (HLQ). This covers 9 key domains of health literacy using 44 validated questions. The data is then clustered to create stories or “vignettes” that describe the typical health literacy needs of people within that population. Stakeholders can then work co-productively with these vignettes in structured workshops to design and implement quality improvements that respond to those health literacy needs. The Deakin team have worked with organisations across the UK to pioneer the Ophelia approach.

This Interactive session will present the background to the Ophelia process and the Health Literacy Questionnaire, explore the practical experiences of implementation across exemplar sites in Scotland, Wales and England and then provide a facilitated discussion between audience and panel around the potential of the Ophelia process to improve health literacy on a population scale.

Learner-centred Health Literacy

J Solla
Community Health and Learning Foundation

This workshop will look at learner-centred health literacy, outlining the Health Literacy programmes and training delivered by the Community Health and Learning Foundation in deprived communities in England.

The aim of the workshop will be to:
- Provide an overview of Skilled for Health and HEY! programmes and resources
- Show the impacts such programmes have on learners
- Explore opportunities to use the Skilled for Health resources in their own settings

Towards Sexual Health Literacy

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Chair: L McDaid[2]
[1]Applied Epidemiology Unit, Ontario HIV Treatment Network
[2]MRC/CSO Social and Public Health Sciences Unit, University of Glasgow
[3]Glasgow Caledonian University

Sexual health is an integral part of overall health. However, we argue that conceptualisations of health literacy, which have tended to focus on general health, fail to fully incorporate the specific needs and concerns of sexual health. Being sexually healthy involves managing sexual relationships and healthcare, negotiating sexual pressures, executing protective strategies and managing the moral stigma of STIs, sexual identities and social norms of acceptable sexual behaviour. Sexual encounters comprise multiple, interacting, contextual and interpersonal elements, such that applying learned information to make healthy decisions in sexual scenarios entails employing interpersonal skills to negotiate and communicate with sexual partners about complex risk information in dynamic and changing circumstances (‘in the heat of the sexual moment’). Sexual health literacy, then, encompasses a wide range of knowledge and skills to be accessed, consumed and negotiated in a range of situations and environments. Moreover, the growing biomedicalisation of sexual health care, coupled with increasing use of new technologies and emphasis on self-testing/management raises new challenges and further complicates and already complex, uneven, and uncharted sexual health landscape. In this symposium, we will explore what sexual health literacy might look like in this dynamic and changing context by exploring key theoretical approaches and empirical work. Four presentations will be made before opening up the session to a wider discussion about what sexual health literacy might look like and how researchers, practitioners and communities can take this forward. These presentations will focus on:

- An emerging sexual health literacy framework for gay and bisexual men to emerge from a CIHR-funded workshop
- Understanding the digital sexual health literacy of young people
- Exploring HIV literacy in relation to new biomedical HIV prevention interventions
- Considering the role of new sexual health technologies in practice and the implications for public health intervention

Poster Presentations

1	Hannah Cowan	Exploring the relationship between numeracy, mental health, and debt: the forgotten aspect of health literacy
2	Jonathan Berry	Testing materials about breast awareness with people with lower levels of health literacy in England and Scotland
3	Samantha Davis	Health Literacy in action - or just messing about on the river?
4	Carol Maddock	The role of Social Support Networks in the Dementia Literacy of Older People
5	Claire Murray	Communicating risk clearly: a project to develop best practice guidance
6	Lesley Malloy-Weir	Charting a course to identify the contribution(s) of health literacy and numeracy to treatment decisions
7	Lindsey Murphy	Developing an online health literacy resource and network to support health and social care staff
8	Donna Athanasopoulos	Clear to all
9	Jason Gordon	Removing barriers to Accessing Vital Health Information Online
10	Laura Mackey	Healthcare professionals’ attitudes towards health literacy, and the clinical encounter with chronic pain patients
11	Liesbeth de Wit	Towards Critical Health Literate Communities: A Qualitative Systematic Review and data synthesis of Community-Based Participatory Action initiatives
12	Susie Sykes	Using Community Development to Build Critical Health Literacy
13	Lesley Grant	Workload Involved in the Outcome Evaluation of the Glasgow Deep End Links Worker Programme
14	Paula McDonald	Should medical journals set readability targets for contributors?
15	Kellie Smith	How readable is the BMJ?
16	Daron Aslanyan	GP websites – are they readable?
17	Ghalib Khan	Bilingual Pharmacy Dispensing Labels.

Exploring the relationship between numeracy, mental health, and debt: the forgotten aspect of health literacy

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The problem: Research indicates that there is an association between mental health and numeracy. Evidence from Canada suggests that higher numeracy levels help protect people from experiencing psychological distress (Caron et al., 2007). Similarly, data from the British Cohort Study identifies that poor mental health is associated more greatly with poor numeracy skills than literacy skills (Parsons & Bynner, 2005). However, there is currently no theoretical explanation as to why this relationship exists. We did some exploratory work to understand this relationship in more detail.

The approach: We carried out an investigative literature review to understand the relationship between numeracy skills and mental health. We then discussed our findings with experts in the field, including staff at the Mental Health Foundation, Solent Minds, Cheshire and Wirral Partnerships Trust, and Nottingham Recovery College to validate the theory behind these findings.

Findings: Findings suggest that the relationship between numeracy and mental health is explained through the relationship with debt. There is strong evidence of a relationship between debt and mental health (Sweet et al., 2013; Walsemann & Gee, 2015; Zurlo et al., 2014). Research suggests 25% of people with a diagnosed mental health problem are debt, compared to 9% of the population without a mental health problem. The reverse relationship is also true: people in debt are over three times more likely to have a diagnosed mental health disorder, over four times more likely to have a psychotic disorder, and almost eight times more likely to commit suicide (Richardson et al., 2013).

The relationship between debt and mental health is thus mediated by numeracy, as numeracy is a key element for building people's financial literacy skills. Research from the British Household Panel Survey found that lower self-reported financial capability is strongly associated with psychological disorders, independent of the effects of income, financial resources, and financial shocks (Taylor et al., 2011). However, experts in the field of financial literacy have argued that more emphasis must be placed on the basic numeracy skills required for financial decision-making (Lusardi, 2012; Carpena et al., 2011). Research from the UK has confirmed the association between numeracy and financial capability, where a person's numeracy skills have strong correlations with their wealth, financial knowledge, and the complexity of the financial assets with which they choose to engage (Banks & Oldfield, 2007). The level of numeracy needed to understand and plan for these financial situations could therefore be having an effect on people's abilities to manage their money, thus affecting their mental health. Lower numeracy skills may also make it harder to refrain from building debt when someone is experiencing a mental health problem.

Consequences: Mental health can often be neglected in conversations around health literacy, but this research suggests that further investigation must be taken to explore the relationship between numeracy and mental health. Numeracy classes should be designed specifically around financial capability, and trialled as both an intervention and a prevention measure to build people's confidence and competence around managing money.

Testing materials about breast awareness with people with lower levels of health literacy in England and Scotland

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[2]Breast Cancer Care

The idea: To test out via the use of facilitated focus groups whether people with lower levels of health literacy were able to follow guidance about how to look after their breasts and spot any warning signs, contained in the three items of easy to read information produced by Breast Cancer Care.

Why it matters: Around 55,000 people are diagnosed with breast cancer each year in the UK. Over the years treatments have improved and many people recover from breast cancer. However, the earlier it's diagnosed the more successful treatment is likely to be. Although women between the ages of 50 and 70 are invited to routine breast screening, it's important for women (and men, 350 men are also diagnosed with breast cancer each year) to be breast aware. This is about knowing the signs and symptoms of breast cancer and what's normal for them, checking their breasts and reporting any change to their GP.

Research has shown that women from specific groups have poorer outcomes for breast cancer and may not report symptoms, or not know what symptoms they should report. Breast Cancer Care wants to ensure that lack of understanding of symptoms and what to do if a breast change is found is not a barrier. Breast Cancer Care felt that this was likely to be particularly marked among people with lower health literacy levels who are frequently not consulted with.

Breast Cancer Care commissioned the CHLF to conduct some focus groups with communities that tend to have poorer outcomes for breast cancer and who also tend to have lower levels of health literacy. The CHLF recruited a total of 11 focus groups across England and Scotland with a total of 95 participants. The groups were asked to appraise three items all of which aim to improve people's understanding of breast cancer risk and the signs and symptoms of it. They were:

- a mini guide called 'Taking care of your breasts'
- a poster entitled 'Am I at risk?'
- an infographic with the heading 'Not just a lump'.

Among the findings were that:

- words of multiple meaning and ambiguity are problematic
- the use of medical terminology was confusing
- diagrams sometimes caused confusion
- not everyone knew the core breast awareness message.

Next steps: Following the focus groups and the CHLF report, Breast Cancer Care:

- amended the infographic to improve the design and clarity
- started work on a range of publications they are calling 'clear text'
- made changes to the standard wording they use in their information to remove ambiguity.

The latter two are ongoing.

Risks: The information may still be too complex for some communities and we may need to consider how we take that into account when developing new resources. It will be hard to identify direct impact on general breast awareness and screening uptake.

Health Literacy in action - or just messing about on the river?

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The idea: *Project Pugwash* was a water-based health literacy project which ran successfully from 2008 up until the reorganisation of the Primary Care Trusts in 2012/3. In partnership with the Canals & River Trust (formerly British Waterways) and a local charity, Safe Anchor Trust, the local PCT's Community & Health Development team delivered seasonal participatory programmes uniquely designed to engage the 'hard to reach'. Characteristically, those defined as 'hard to reach' resided in neighbourhoods with high multiple deprivation, had a higher incidence of poor health - particularly in relation to mental health and managing long term conditions and could be described as having very low basic literacy and numeracy skills (JSNA, 2008-2013).

The demand for *Project Pugwash* led to rapid project expansion and within just two years the delivery schedule had grown to accommodate the basic day programme; boating courses; tow-path tidy days; environmental clean-ups; guerrilla planting for fruit & veg; waterside community fetes and latterly volunteering.

Why it matters: *Project Pugwash* mattered to everyone who got involved: 600 **new** participants each and every year. Young or old (the youngest to sail was just 8 months old and the oldest was 99!), male or female (the project attracted just as many males as females which is rare) and people of differing abilities and backgrounds. *Project Pugwash* brought people together, encouraged them to try something new, and through motivation and modelling techniques taught people the valuable skills of how to lead a healthy, structured day which included the basics of good eating habits; doing some regular physical exercise; having a hobby and being with others. *Project Pugwash* also mattered to the many 3rd sector organisations and local community groups who supported the vulnerable people we took on board as passengers and volunteers. In their testimonies, *Project Pugwash* gave their clients/members something to look forward to, a much needed friendship circle and the feeling that they could at last make a useful contribution to their locality.

Severe cuts to funds and personnel followed the reorganisation of the PCTs and although many *Project Pugwash* passengers volunteered to help keep the project afloat, they lacked the knowledge and skills needed to do so and so, in 2013, *Project Pugwash* was mothballed.

Next steps: *Project Pugwash* made a huge impact - both locally and regionally - and has not been forgotten. Its actual success and future potential were sadly commuted by political restructuring and the pressure to extend austerity. It was simply a victim of the times. Now that the dust has settled, it is time to evaluate *Project Pugwash* and to learn from such an evaluation not only what makes a successful health literacy initiative, but how it might be revived to stay afloat during leaner times.

Risks: A partnership evaluation between Higher Educational Institutions interested in innovative and sustainable health literacy approaches would be low risk.

The role of Social Support Networks in the Dementia Literacy of Older People

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The problem: There are increasing numbers of people with dementia worldwide. Currently one in 3 people over the age of 65 will develop dementia, however people over 65 know less about dementia than someone in their twenties. 'Dementia literacy' is a component of the overarching concept of Health Literacy and can be considered as ‘knowledge and beliefs regarding dementia that aids recognition, management, or prevention’. Nutbeam’s asset model of Health Literacy suggests that it can be developed through tailored information, education and communication over the lifecourse; and more recent research shows that social support networks can moderate the effects of low health literacy. Older people with different social support network types may access and share information differently even with similar medical conditions.

The approach: The study will draw on three data sources to estimate health literacy in the social support networks of older people in Wales. Qualitative interviews used in CFAS II Wales explored differences in dementia related support expectations across network types. A framework approach was used to analyse the data and generate themes for the development of an interview schedule for a further thirty in-depth interviews conducted to explore individuals dementia experience, awareness and knowledge as well as identification of information needs, preferred sources of information and mechanisms of sharing information in their social networks.

Findings: Initial analysis of the data has indicated that there are gaps in older people’s knowledge and understanding of dementia and recognition of the symptoms (dementia literacy). There are different expectations of who will provide the respondents with dementia related support covering a variety of everyday activities including for example shopping trips, attending hospital appointments and managing health care in general. There was also uncertainty about levels of support that may be available to individuals within their communities who may develop dementia and perhaps more importantly concerns about ‘interfering’ or ‘getting things wrong’ if help was offered. Within the wider community general themes included the difference between provision of support to someone with a physical problem compared to dementia. Attitudes to dementia varied even where personal experience was included.

Consequences: This study will provide more information about older peoples dementia literacy status, support expectations, information needs, preferred information sources and how the distribution of health literacy may occur within social support networks, with individuals or several people within the network taking on a health literacy mediator role. It will enable recommendations to be made concerning the types of interventions that are needed to improve dementia literacy and that are likely to be effective for people who have different types of social networks. Interventions to support learning within social networks and that include the development of skills and tools that will allow co-management of different health challenges could be considered. Likewise community-based interventions focused on older people with dementia and their social networks may help those affected by dementia to remain and live more easily in their communities.

Communicating risk clearly: a project to develop best practice guidance

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The idea: The aim of the project was to develop and share practical steps to support the producers and providers of health information to clearly communicate risk in a way patients and service users understand.

Why it matters: Risks and statistics are an essential part of health information for patients, service users and the public. What is a person's risk of developing a particular condition in their lifetime, or of having a certain symptom? What is the chance of a treatment or procedure working? What is the risk of getting different side-effects? And can people change these risk factors?

Yet, many patients are unable to comprehend basic statistics, never mind navigate their way through the reams of data that may come with health information, comparing treatment options for example.
People who produce and provide health information have a vital job to support patients through the minefield of data and figures to help them feel confident in making their own decisions. However, evidence suggests that too many health information materials do not fully address risk in a clear and understandable way.
This project has sought to develop the UK's first producer led guidance and best practice to help improve skills and understanding in this area.

Next steps: Between March 2014 and August 2015 we:

- Held three information gathering events with 100 health information professionals to understand key challenges and learning points
- Conducted a literature review to identify the latest evidence on how to communicate risk clearly
- Developed a series of key steps to support the clear communication of risk and a toolkit to provide practical support
- Shared the key steps with the PiF membership for review and comments
- Created a toolkit and factsheets to support health information professionals follow the best practice and key steps in their work.

The outputs of the project have been shared with 2,500 people working in the field of health. We are holding a 1 day learning event in January 2016 to further share the findings of the project and connect experts in the field of risk with health information professionals.

Risks: The two key risks for the project were that the outputs would not be useful or accurate.

It was vital that the process engaged health information professionals from the initial concept development to ensure the best practice and resources were relevant and provided useful support for their work. We addressed this risk through engaging PiF members and other health information professionals at key points at the outset and through the development of the project; and by working with two PiF members to create the factsheets.

It was vital that the outputs of the project were based on the latest evidence in this area, and that they were accurate and clear. We addressed this risk through rooting the best practice and key steps in the literature review; and by having the project outputs reviewed by an established expert in risk communication.

Charting a course to identify the contribution(s) of health literacy and numeracy to treatment decisions

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The problem: Internationally, a trend is growing toward the implementation, and in some cases legislation, of shared decision making and patient decision aids in clinical practice. This trend is occurring at a time when low health literacy and numeracy are widespread in many countries and low numeracy has been identified as a problem in health professionals. These conditions increase the likelihood of patients and health professionals being ill-equipped to engage in treatment decision making encounters. Two scoping reviews have also found the existing evidence to be extremely limited in terms of its ability to: (1) identify the unique and shared contributions of health literacy and numeracy to the treatment decision making process, and (2) inform policy and practice so that negative outcomes attributable to low health literacy or numeracy are minimized. To address this problem, we propose a research agenda that will engage stakeholders that have been marginalized in previous research (i.e., certain patient populations, health professionals, and policymakers) and address the major knowledge gaps and multiple methodological problems identified in these two scoping reviews.

The approach: A step-wise and iterative approach to the problem is recommended. In Step 1, a shared definition and interpretation of health literacy and numeracy that is specific to the treatment decision making context of interest is identified. In Step 2, valid and reliable measures are developed to reflect the definitions identified in Step 1. These measures must be able to assess health literacy and numeracy in both patients and health professionals and must be used consistently by researchers. In Step 3, hypotheses, theories and/or conceptual models of empirical relationships between patients' and health professionals' health literacy, numeracy, and the three stages of the treatment decision making process (information exchange, deliberation, deciding on the treatment to implement) are generated. In Step 4, the hypotheses, theories, and models generated in Step 3 are rigorously tested in actual clinical settings to determine the strength, direction, and stability of relationships across the three stages and over time. In Step 5, the findings derived in Step 4 are interpreted and used to refine the hypotheses, theories, and models identified in Step 3. In Step 6, any new or refined hypothesis, theories or models emerging in Step 5 are empirically tested. A deliberative dialogue should be used to engage stakeholders (i.e., patients, policymakers, health professionals) in Steps 1, 2, 3, and 5 to guide the research and help interpret the findings. Steps 1 through 6 should also be replicated in different treatment settings to determine the extent to which the findings are generalizable.

Findings: Our proposed research agenda is *inclusive* (i.e., reflecting views from multiple stakeholders); *sensitive* to the multi-dimensional, dynamic, and context-dependent nature of health literacy, numeracy, and treatment decision making; and *responsive* (i.e., flexible in terms of its application).

Consequences: Our proposed research agenda will help policymakers and practitioners to avoid negative outcomes associated with the use of shared decision and patient decision aids in settings where patients and/or health professionals possess low health literacy or numeracy.

Developing an online health literacy resource and network to support health and social care staff

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The idea: 'Making it Easy: a health literacy action plan for Scotland' (Scottish Government, 2014) aims to enable Scotland to be a health literate society. The Knowledge Services Group, NHS Education for Scotland (NES) are responsible for actions in the plan including the development of an online resource to promote the development and spread of health literacy tools and innovations.

The Health Literacy Place (www.healthliteracyplace.org.uk) has been developed as the 'go to' place for health literacy support and information in Scotland and was launched in October 2015 as part of Health Literacy Month. The website provides resources and information under the following headings as well as sections where staff can submit case studies, blogs and news.

- Tools and Techniques
- Learning and Development
- Evidence
- Resource library.

The Knowledge Network, hosted by NES is an online knowledge and learning resource for health and social care staff. People Connect, hosted on the Knowledge Network, is a social network and online discussion tool where staff can network, collaborate, and share ideas/experiences. This online network is being used to join up people interested in health literacy alongside the formation of a health literacy supporter network to raise awareness of health literacy messages at a local level. At October 2015 a total of 25 supporters are signed up across the 14 NHS Board areas in Scotland, this continues to grow.

To measure and evaluate health literacy activities related to the website and building workforce capability, an outcome and evaluation framework has been developed, informed by knowledge into action principles (NHS Scotland, 2012).

Why it matters: This work contributes to the national action plan for health literacy in Scotland as well The Healthcare Quality Strategy for Scotland (Scottish Government, 2010). Health literacy fits with national priority areas such as person-centred, patient safety and reducing health inequalities.

The health and social care workforce in Scotland are in a prime position to promote and support health literacy. This work provides the workforce with a central resource for health literacy support and information which they can implement at a local level and also allows them to connect with others in their area and nationally with health literacy interests. This strand of work will improve the sustainability of health literacy activity across Scotland as staff build a central resource and network for health literacy share and spread health literacy experiences and innovation.

Next steps: The website and supporter network continues to grow as people are encouraged to become more involved through blogs and discussions to share experiences and ideas. A training programme to raise awareness of health literacy with supporters will be rolled out over the coming months.

The outcome and evaluation framework for the programme and undertaking activities to support the evaluation will be further developed and implemented.

Risks:

- Lack of interest from professionals –based on work so far and interest received this is gathering momentum
- Sustainability – growing network of supporters in various areas/disciplines
- Evidencing impact – robust evaluation framework is in place.

Clear to all
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The idea: The NHS Greater Glasgow & Clyde Health Literacy Steering Group has been set up to improve staff awareness and to highlight to staff that Health Literacy is everyone’s responsibility.

Why it matters: To support patients through all stages of their health journey, ensuring that they have information that is patient centred. All NHS Greater Glasgow & Clyde information is made accessible to patients under our Clear to all policy.

Next steps: Produce Health Literacy action plan that will inform staff on the ways that health information is accessed as well as guidance on producing information.

Risks: Staff not being released for training on Health Literacy.

Removing barriers to Accessing Vital Health Information Online

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The idea: The NHS need to make savings of £30bn by 2020 and we all have a part to play in achieving this. Greater availability of health information and acceptance of the shared responsibility all UK citizens have for their health would make lasting savings to the NHS. Online technology plays a vital role in achieving wider health literacy in the UK as it provides the most effective and cost-efficient way of relaying health information nationwide. However 1 in 5 UK adults are unable or incapable of accessing health information online. There are many reasons for this: disability, English language challenges, low digital literacy, age, print and literacy challenges. In this presentation we would explore the barriers to accessing health information online, before looking at some solutions to the problem.

Why it matters: If UK citizens are to embrace their collective health responsibility, and help cut the NHS funding gap by 2020, accessible health literacy is key and digital technology has a crucial role to play.

Next steps: Explore solutions to digital health literacy exclusion and select solutions that are right for your Trust.

Risks: None

Healthcare professionals' attitudes towards health literacy, and the clinical encounter with chronic pain patients

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The problem: One in four people in Ireland suffer from chronic pain, and best practice guidelines advocate the use of self-management and patient-centred approaches to maximize quality of life. The impact of limited health literacy (HL) in this patient population is relatively unknown, and very little empirical data exists regarding the use of HL practices or policies in a pain management, healthcare based setting. Therefore, this study aims to explore healthcare professionals' attitudes regarding the role of HL in clinical practice, and its impact on patient outcomes.

The approach: This qualitative study utilised semi-structured interviews to capture healthcare professionals' perspectives on HL. Healthcare professionals specialising in pain management were included: pain consultants, physiotherapists, nurses, and psychologists. A battery of questions was derived from current HL research, focussing on interviewees' knowledge of HL, recognising those at risk of low HL, the skills required to identify and manage those with low HL, and the economic burden of low HL. The interviews were transcribed verbatim, coded, and inter and intra-reliability of the codes was determined by two reviewers. Common themes were then identified and reported accordingly.

Findings: Sixteen healthcare professionals (four per discipline) were included in the study, with four main themes emerging from the interviews: 1) Lack of formal HL awareness in healthcare settings, 2) HL vital for understanding and engaging in treatments, 3) Varying interventions for low HL, and 4) barriers to addressing low HL in patients.

The majority of healthcare professionals were not familiar with the term 'health literacy', but were aware of the concept with respect to their clinical practice. In addition, all agreed that HL was integral to adopting self-management behaviours – a mainstay for chronic disease treatments. However, healthcare professionals' knowledge of HL-sensitive interventions varied, and was based on subjective experience as opposed to evidence-based practice. Furthermore, most cited time-restraints as a primary barrier to facilitating HL skills in their patients, despite acknowledging that it was their responsibility to do so.

Conclusions: These findings suggest that healthcare professionals need further support from health services and policy makers to incorporate HL-sensitive interventions into their practice.

Towards Critical Health Literate Communities: A Qualitative Systematic Review and data synthesis of Community-Based Participatory Action initiatives

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The problem: Critical Health Literacy (CHL) supports older adults with making informed health decisions and taking actions, in their own cultural context, for the health and wellbeing of themselves and their community. A Community-Based Participatory Action (CBPA) approach could support CHL of older adults in their community and empower them, but research on strengthening CHL at a community level is scarce. Therefore, the aim of this qualitative systematic review and data synthesis is to explore how CBPA initiatives address the CHL of older adults in their community context.

The approach: A literature search was conducted of five electronic databases, WHO's WHOLIS database, IROHLA's database of systematic reviews, and reference lists. Search strings encompassed terms related to 'CBPA initiatives' and 'older adults'. CHL was assessed for in each study to ensure a comprehensive set of evidence. Two reviewers independently screened titles and abstracts, as well as the quality of the methodological and CBPA elements of the studies. The results sections of the included studies were analyzed through qualitative text analysis, coding and searching for commonalities, differences, patterns and themes.

Findings: The selection procedure resulted in 2,260 articles of which 23 were included for data synthesis. None of the studies explicitly aimed at strengthening CHL. Three clusters of CHL elements could be identified: 1) Knowledge of health information and social determinants of health: awareness, needs and perceptions about health and social issues; 2) Collaborative learning: formal ways of exchanging health knowledge among peers and other community members; 3) Communal actions: individual and community activities for health and wellbeing, and challenges of people's social and cultural context.

Consequences: With this qualitative systematic review and data synthesis we explored CHL at the community level. Our comprehensive search strategy enabled us to identify a set of CBPA initiatives that strengthen CHL of older adults within their community. This evidence shows how elements of CHL are embedded in older adults' social and cultural context, thus illustrating how CHL can be approached at a community level. This review offers health experts and policy makers' evidence that a CBPA approach could strengthen CHL at the community level, in different social and cultural contexts.

Using Community Development to Build Critical Health Literacy

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The problem: Critical health literacy is a domain of health literacy that has been presented as existing at both individual and community level. However, critical health literacy is the least well explored and researched domain of health literacy and there are few examples of initiatives designed specifically to build it. Despite clear overlaps with the field of community development, critical health literacy is also almost entirely absent from the literature in this area.

By building critical health literacy it is suggested that individuals and communities: can become informed about the health issues that do or may affect them, are motivated and able to access, manage, understand and critically analyse information on health issues, have the skills to effectively and critically communicate with professionals about health issues and make informed decisions about their own health. Importantly, they will also understand the wider social and political causes of health issues and will be motivated and skilled to act to challenge and campaign for change at a structural level. Individuals and communities with this skill set are therefore important self-managers of their own and society's health and can become important actors in achieving positive health outcomes and health equity.

Given the potential contribution that the operationalisation of critical health literacy has to make, work is needed to identify processes for its development and to explore the relevance of community development as a home for this area of work.

The approach: Case study research has been undertaken to explore whether and how a community development project has worked to develop each of the attributes of critical health literacy. The attributes examined were:

- Advanced personal and social skills
- Advanced Information and Analytical Skills
- Health Knowledge
- Effective Interaction between Services and Individuals
- Informed decision making
- Empowerment and Political Action
- CHL as a learnt and movable state.

Multiple sources of data including; documents, interviews, photographs, audio recordings, social media and field notes were gathered from the project. These were scrutinised and any evidence of the development of each of the attributes of critical health literacy was extracted.

Findings: The case study demonstrated that the community development project, despite not making explicit claims to be building critical health literacy, did work to develop each of the attributes of critical health literacy. Through the case study a range of processes were identified that can be used to build critical health literacy.

Consequences: The findings from this case study are important in providing illustration of techniques that can be used to develop critical health literacy with disadvantaged communities. It also demonstrates the relevance of the principles and processes of community development in the building of critical health literacy. Critical health literacy currently sits primarily within the realm of health but introducing the concept more fully into the discourse and practice of community development, may offer it a more natural home and result in more work being done to operationalise it. From this, the potential outcomes of work in this area can then be researched.

Workload Involved in the Outcome Evaluation of the Glasgow Deep End Links Worker Programme

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The problem: Engaging patients, particularly those living in socially deprived areas in research is challenging. For example, the response rate to the 2013/2014 Scottish Health and Social Care Experience Survey ranged from 13 per cent for the patients living in the most deprived areas to 24 per cent for patients living in the least deprived areas (http://www.gov.scot/Publications/2015/03/8892/8)

The approach: The Links Worker Programme, funded by the Scottish Government, is being delivered by the Health and Social Care Alliance, Scotland. As part of this programme, 7 of the 15 Deep End GP Practices that applied to take part in the Programme were selected to have an attached Links Worker (LW). LWs facilitate links between general practice and community organisations; encouraging patient autonomy and community development. The 8 Practices that were not selected delivered care as normal, and agreed for data to be collected as comparator Practices for an evaluation of this Programme. Since September 2014, the University of Glasgow has been undertaking an independent evaluation of the Programme. This is based on a quasi-experimental design, with embedded, theory-led process evaluation. Using mixed quantitative and qualitative methods, it is assessing the impact of the Programme on a range of short, medium and longer term outcomes at patient, practice and community levels; and to determine the robustness, feasibility and acceptability of the Programme's theories of change. This report concerns the workload involved in engaging patients in the 7 intervention practices to obtain baseline quantitative outcome measures for the evaluation.

Findings: Using an electronic database all attempted contact with service providers and potential study participants are recorded. To date, 298 of the 589 patients (51%) have consented and completed baseline questionnaires. This has involved 5,684 contacts. Reasons for these include checking contact details, establishing first contact, sending study information and questionnaires, encouraging return of completed study documents and acknowledging receipt of completed questionnaires. The number of contacts concerning each potential participant has ranged from 1 to 41 (mean 9.6, standard deviation 5.68). These were telephone calls/texts (51%), letters (25%), face-to-face meeting (0.1%) and miscellaneous (4%). 2 Virtually all contacts have been made by the study co-ordinator (LG), the study's fulltime dedicated recruitment resource. Most contact attempts were made within usual office hours, but 1 hour was dedicated to this two evenings each week and 2 hours every Sunday afternoon.

Consequences: Engaging Deep End patients in research is possible but is labour intensive. In this study, this required a dedicated full time staff member, some out-of-hours work and careful management of contacts with service providers and potential study participants.

Should medical journals set readability targets for contributors?

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The idea: Should medical journals set readability targets for contributors?

Why it matters: An important aspect of health literacy is the ability to access and understand information to make decisions about health. Much of the current activity in health literacy is focussed, rightly, on the need to make information and services accessible to people with low literacy levels. There are, however, two groups of people with higher literacy levels who wish to access health information and who have different needs.
The first group is healthcare consumers: patients with high literacy levels and technological skills, who wish to research their own condition. In a post-modern society, patients want to be in charge of decisions about their health and need access to the information that will help them make these decisions. Examples of this sort of patient are Peter Goetze and Dave DeBronkhart, also known as e-patient Dave.
Tim Berners-Lee, inventor of the Web suggests that the next big thing is "not to have your browser go out and find other people's articles about the data, but the raw data". The rise of the internet and the decline of the knowledge-based professions both mean that the healthcare consumer will increasingly want to access source data in medicine. A principal source of this is medical journals. The move towards open-access medical journals means that this data is more accessible than ever – but is it understandable? A number of researchers have found that medical articles are written in an "unreadable" writing style, as shown by readability indices such as the Flesch score.

A second group who need to be able to access and understand medical journals are healthcare workers who speak English as a second language. The top 50 most cited general medicine journals are all published in English. A few are also available in local languages, but on the whole, English is needed to access medical literature. Looking at the global burden of disease, however, a large proportion of it is in non-English-speaking countries. Even in countries such as South Africa and India where English is used as an official language, it will generally be the second language for most people, so complex language will be harder to understand.

Next steps: Research applications now have to be accompanied by lay summaries which the Medical Research Council advises should be "written for a reader of a mid-market tabloid newspaper." Medical journals could do the same. They could also consider setting readability targets for articles. Medical schools should teach plain English.

Risk: e-patients may need help to appraise information, but this is not a reason to make it inaccessible
Medical prose needs to be precise, and some long words can't be avoided, but readability scores can be adapted to allow for this.

How readable is the BMJ?

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The problem: The BMJ regularly carries articles that may be of relevance to interested patients, who may hear about topical articles through the media or may purposefully search for a particular topic. They may be able to access the BMJ on-line by a number of routes. Recent examples of articles that might be of interest to patients include a comparison of CBT and antidepressants for acute depression, a systematic review showing that calcium supplements do not prevent fractures and a comparison of the safety and efficacy of two different methods of female sterilisation. However, a number of studies in the past have found that articles in medical journals are written in an "unreadable" style, making them difficult for a lay reader to access.

The approach: All of the editorials and all of the research articles in two issues of the BMJ were assessed for readability using the Flesch reading ease score and the FOGG index.

The most "unreadable" article was then rewritten in an attempt to improve the readability score.

Findings: To be presented.

Consequences: To be presented.

GP websites – are they readable?

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The problem: GP websites have the potential to be a useful source of information for the public but often do not contain information that is standardised or requires a high level of health literacy to understand. In addition, practice information is duplicated or differs on NHS/non-NHS websites which could lead to confusion. Overall, this makes it hard for the public to quickly and efficiency find and understand health and GP access information.

The approach: A randomly chosen subsection of the 44 practices in Brighton and Hove was analysed for:

- Readability of information (Flesch Reading Ease, Simple Measure of Gobbledygook (SMOG) test, Gunning Fog Index)
- Categories of information (registration, appointments, services, health information)

Findings: To be presented.

Consequences:

- Medical students will improve their knowledge of health literacy and their skills in writing plain English.
- The analysed, improved versions will be fed back to the local GP practices.
- Need for standardised, information on GP services across NHS/non-NHS websites.

Bilingual Pharmacy Dispensing Labels.

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Medical Information for Ethnic Minorities (MIEM)

The problem:
Medication adherence is essential for effective treatment and patient compliance is integrally linked to the patient's understanding of their medicines. Furthermore, studies have shown that a patient's inability to understand English leads to compliance problems, naturally causing medication errors and adverse drug reactions. Patients that are unable to speak English are also less likely to understand healthcare professionals and written instructions.

According to the 2011 Census, more than 5 million people in the UK speak English as a second language, of which a million have a poor ability or cannot communicate in English.

The approach:
As a source of medical information, the pharmacy dispensing label's significance should not be underestimated, as doctors and pharmacists frequently miss opportunities to counsel patients. For many patients, the pharmacy label is the only source of information about how to use their medicines.
BME patients with limited ability in English have to get communication interpreted or translated, however, there is no professional solution in the pharmacy environment. Such patients often rely upon bilingual pharmacy staff if

available or family and friends. This removes any confidentiality that the patient may wish to have by relying on other.

We want to see if bilingual pharmacy labels can reduce the language and cultural barrier these patients face and help improve patients experience in taking medication, use them as directed in a safe and appropriate manner and its positive impact on adherence.

Next steps:
We have just started a 6 months trial in 15 community pharmacies in London, funded by NHS Health Education England South London, which will be evaluated by Portsmouth University.

Attendance Certificate and Evaluation

We would really welcome your evaluation of the conference and will be sending you a link to an online questionnaire. Once you have completed it, you will receive an attendance certificate.

PLEASE COMPLETE THE EVALUATION BY 15th April 2016.